



**National  
Multiple Sclerosis  
Society**  
Greater Illinois  
Chapter

January 22, 2014

Comments of National Multiple Sclerosis Society, Greater Illinois Chapter on The Illinois 1115  
Waiver Application

The Greater Illinois Chapter of the National Multiple Sclerosis (MS) Society, on behalf of the approximately 20,000 Illinoisans with MS, thanks you for the opportunity to submit comments in regard to Improving Access to Community based Long-Term Supports and Services through expanding eligibility.

Background

In 2008 the Illinois General Assembly voted to improve access to home services for people living with multiple sclerosis, by instituting a Home and Community Based Support (HCBS) program for persons with MS.. The services and eligibility for this MS program would have been similar to the HCBS program for adults with disabilities, but would have exempted retirement assets and spousal life insurance policies. In 2008, the Legislators recognized the long-term savings of this proactive support by preventing total dependence on government funds such as unemployment compensation for care giving spouse; health care costs for the entire family due to loss of employment based health insurance and housing costs because of loss of primary residence. Unfortunately, due to the state's budget deficit this initiative was never funded.

We believe the Path to Transformation – 1115 waiver, the 1915k or other available waivers are opportunities to finally increase eligibility and provide these services to needed individuals by exempting retirement assets and spousal life insurance policies for applicants with disabilities under the age of 65. Exempting spousal assets and income for all applicants with disabilities is another option. This will improve access by eliminating requirements that force people living with MS and other debilitating conditions to deplete their assets in order to be eligible for services.

What is Multiple Sclerosis?

Multiple sclerosis (MS), an unpredictable, often disabling disease of the central nervous system,



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interrupts the flow of information within the brain, and between the brain and body. Symptoms may be mild, such as numbness in the limbs, or severe, such as paralysis or loss of vision. One of the most unique aspects of MS is that the progress, severity, and specific symptoms of MS are unpredictable and vary from one person to another. While there are cases of pediatric MS, most people with MS are diagnosed between the ages of 20 and 50 which leads to another unique quality of MS—that once diagnosed, the unpredictable physical and emotional effects are life-long.

For most people with MS, the disease is initially characterized by periods when symptoms intensify (relapses) and quiet periods (remissions). However because MS is a progressive disease, as time goes along, many individuals will transition into a more progressed course with continuously increasing disability. Whatever the initial disease course, the future is uncertain for anyone with an MS diagnosis. .

### Financial Burden

- A recent study of medical bankruptcy (Himmelstein et al, 2009) found that 62.1% of all personal bankruptcies in the U.S. were related to medical costs. The authors reported that: among common diagnoses, nonstroke neurologic illnesses such as multiple sclerosis were associated with the highest out-of-pocket expenditures (mean \$34,167), followed by diabetes (\$26,971), injuries (\$25,096), stroke (\$23,380), mental illnesses (\$23,178), and heart disease (\$21,955). (p. 4)
- Median out of pocket costs for health care among people with MS (excluding insurance premiums) was almost twice as much as the general population (Minden et al, 2007).
- The costs associated with MS increase with greater disability. Costs for severely disabled individuals are more than twice those for persons with relatively mild disease. (Kobelt, et al, 2004)



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### Long-term Services and Supports Needs of People with MS

Approximately 20-25% of individuals with MS (currently, 4-5,000 Illinois citizens) need long-term care services. People with MS often require assistance with activities of daily living such as bathing, dressing, eating, walking, and toileting and/or instrumental activities of daily living such as housekeeping and managing finances. While some require assistance for a few hours a week, others need full-time assistance.

- More than a quarter of people with MS use some form of home care but over 80% of this care is provided by unpaid caregivers, mainly family members and, in many cases, youngsters. (Whetten-Goldstein et al, 1998; Sonya Slifka, 2006)
- In a survey of caregivers' perception of predictors of nursing home placement, aging, bowel dysfunction, poorer health, functional decline in the person with MS, and caregiver burden were associated with increased probability of future admission. Higher family income and greater satisfaction with access to MS-focused care were associated with lower risk of nursing home admission. (Buchanan et al, 2010)

### MS is a Family Affair

Multiple sclerosis is a family disease, but shouldn't destroy the family. For people who are experiencing the disabling effects of MS (i.e. extreme fatigue, vision problems, loss of coordination and balance, pain, paralysis or limited mobility, numbness, etc.) raising a family and activities of daily life can be a daunting task affecting the entire family.

Family members are usually the primary providers of care and assistance to their loved ones with MS. They also carry most of the financial burden for long-term care since third party insurance and community social services don't usually underwrite on-going, chronic care services. Stress and tension in households often arise as family members must adapt to new roles and responsibilities. Breakdown of families struggling with daily care issues and financial



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concerns is common.

- The stress of caring for an individual with MS often rests on the family due to lack of financial resources, limited access to public programs, and inadequate and expensive home care programs.
- These stressors strain the entire family, often threatening marriages and placing an unfair burden on family members. Statistics show that people with MS have a higher rate of divorce (19% of people with MS are divorced or separated, compared to only 12% of the general public.).
- Many families are forced to make the difficult decision to place the individual with MS in a nursing home facility, which is not the most appropriate setting for this younger population. The result can be threatened mental and physical health.

#### Community Support.

Since Medicare does not pay for ongoing home care services, when the personal care needs of the individual with MS exceed the resources of the family, access to Medicaid home and community-based services becomes critical. Home health care workers and personal care attendants are often the gateway to independence for people with MS. However, these workers are typically underpaid and often lack benefits such as sick time and health insurance. Adult day centers provide excellent support for the person with MS while also giving his/her family caregivers much needed respite—but more adult day centers that specialize in the MS population—particularly young adults with MS—are needed. Assistive technology, accessible transportation and housing are other key elements in the promotion of independence of people with MS.

#### Long-term Care Principles Important to People with MS

In addition to the principles submitted by Access Living and other disability groups, The National MS Society finds the following LTC principles of utmost importance:

Consumer choice: People with MS must be free to choose from a full range of age appropriate



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and affordable home, community-based, and facility-based health and social service options to meet individual needs and preferences.

Promotion of the least restrictive setting: People with MS should be supported to remain at home and in the community for as long as possible. Nursing home residents should be able to transition back to community living when appropriate and feasible. At the same time, quality, age-appropriate assisted adult day, living and nursing home options must be available.

Access to appropriate and coordinated MS clinical care: People with MS must have affordable access to MS specialists, durable medical equipment, rehabilitation, and treatments. Clinical services must be physically accessible, of high quality, comprehensive in nature, and coordinated among providers.

Support for the caregiver: The role of families in providing long-term care must be recognized and supported, the Society suggests through refundable tax credits for family caregivers and increased access to quality respite care.

Wider range of housing options: A wide range of accessible and affordable housing options including financial assistance for accessibility and modifications for individuals and families must be available.

Decreased financial burden on families: Tax benefits and other sources of services, and financial assistance **not requiring impoverishment for eligibility**, must be available to at least partially offset the high costs of long-term care.

**We also suggest the following specific change to the draft waiver application document:**

Page 76 Physical therapy *There is a State fiscal year maximum of 26 hours, unless additional documentation supports the need for additional hours (up to 52 hours). Services are subject to prior approval by the Operating Agency.* We strongly urge the removal of the 26/52 hours annual cap as it is for children. Physical therapy is often the only treatment available to prevent worsening of the condition. Continuous physical therapy can improve muscle strength, flexibility and balance, preventing costly falls and injuries.

Please contact Jeremy Barewin 312- 423-1124 or Maureen Linehan Howard 773-779-4375 with any questions.



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